



**NATIONAL MENTAL HEALTH  
CONSUMER & CARER FORUM**



## **Submission to the Productivity Commission Inquiry into long term disability care and support**

**August 2010**

The Mental Health Council of Australia (MHCA) is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector, committed to achieving better mental health for all Australians. In addition to its broad membership across the mental health sector, the MHCA auspices the NMHCCF.

The National Mental Health Consumer & Carer Forum (NMHCCF) is the combined national voice for consumers and carers participating in the development of mental health policy and sector development in Australia.

The MHCA and the NMHCCF strongly support the development of a social insurance scheme for disability long term care and support in Australia.

This scheme should be seen as an opportunity to support the human rights of people living with disabilities, many of whom do not now receive the same basic human rights as people without disabilities. For example, insufficient funding and support for disability services do not support many people living with disabilities and their carers in their 'right to an adequate standard of living' or 'right to live in the community'.<sup>1</sup> Better links with other sectors, including housing, health, employment, and others, will underpin the success or failure of this scheme.

A number of historic and sociological drivers have isolated people with psychosocial disability<sup>2</sup> to positions of disenfranchisement from mainstream discussion in the disability sector. It is from this vulnerable position that mental health consumers and carers seek a voice and disability support through this scheme.

### **Introduction**

The Productivity Commission issues paper<sup>3</sup> is very good at describing the problems with the current system. People with psychosocial disability and their carers face a range of difficulties with health and disability services and welcome greater recognition of the disabling nature of persistent mental illness.

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<sup>1</sup> United Nations General Assembly (2006) *Convention on the Rights of Persons with Disabilities*, UN.

<sup>2</sup> There is tension in both the mental health and disability sectors around the most appropriate language to describe persistent mental illness or psychosocial disability. For the purposes of this paper, 'psychosocial disability' is primarily used, although where 'people with mental illness' or 'mental health consumer' is used, it should be taken to read as someone with psychosocial disability related to persistent mental illness.

<sup>3</sup> Productivity Commission (2010) *Disability Care and Support: Productivity Commission Issues Paper, May 2010*, Australian Government: Canberra.

The disabling impact of mental illness is often not as visible as for some other disabilities and is frequently lacking recognition in disability discourse and services. Nevertheless, persistent mental illness is disabling both to a person living with mental illness, as well as impacting heavily on their carers, family and friends. It is reassuring that the Productivity Commission's own paper recognises (in places) the impact of severe mental illness and references the Disability Investment Group report<sup>4</sup> that 25% of people needing constant or frequent support are people with mental illness.<sup>5</sup>

The NMHCCF and the MHCA position is not that disability arising from persistent mental illness is more or less important than disability related to any other illness, syndrome, genetic factor, accident or medical misadventure. Rather, we are concerned how disability related to mental illness has been hidden over many years. We want better disability and support services for *all* people living with a disability, and appropriate supports for their carers, not that it has to be better for only one or another group.

The MHCA and the NMHCCF are pleased Australia has ratified the UN Convention on the Rights of People with Disabilities,<sup>6</sup> including the additional complaints handling process in the Optional Protocol. What this means for the community needs to be well communicated with supports in place for anyone making a complaint to redress a human rights infringement, as they are likely already stretched by having a disabling illness or caring role. We would support a Disability Ombudsman or Commission or similar entity to ensure these important complaints are given the expert attention they deserve. Strong links with the Human Rights Commission would be needed and clear explanation of how the roles would differentiate.

We are concerned about the suggestion in the issues paper that objectives of the UN Convention might need to be 'traded off' against each other to build this scheme. Who would decide which of these objectives is most important? Ideally, a scheme that addresses (or at least attempts to) all of these objectives should be fashioned.

As national entities made up of members across Australia, both the NMHCCF and the MHCA strongly support national consistency across assessments, eligibility and any support related to this scheme. The example provided in the Productivity Commission issues paper outlines perfectly inequity based on geography.<sup>7</sup>

Separating responsibility for funds and services across states or federally may make good sense to governments and bureaucrats, but it does not make sense to those people who are waiting for services or using insufficient or inadequate services 'on the ground'. The divide in responsibility for service provision vs funding (for example,

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<sup>4</sup> Cited in Productivity Commission (2010), op cit, p 9.

<sup>5</sup> Please note that this figure in the issues paper refers to 'mental health'. Obviously, it is people with persistent or severe mental *illness* that means they need such high level support. Mental *health* is not an appropriate catch-all term to use in discussion about disability-related need.

<sup>6</sup> UN (2006), op cit.

<sup>7</sup> Productivity Commission (2010), op cit, p 11. Example outlines how a person who acquires a severe brain injury in a particular street in Tweed Heads receives different levels of support depending on which side of the street they were on and therefore whether they were in NSW or Queensland.

national safety nets but local provision of services dependent on insufficient funding) adds to consumer and carer confusion and lack of a comprehensive approach to support or care.

The issues paper uses 'short-term' disability in most places to be less than six months, but in one place seven-12 months is used. Which is it? Of course, when it is highly unlikely there will be any significant change in disability status over a particular period, re-assessment should be less often. However, clarity is needed about what 'short-term' is by using consumer and carer definitions to do this, acknowledging the impact disability has on their lives.

### **Design elements of the new scheme**

The MHCA and the NMHCCF support the insurance scheme being designed around people with a disability developing their own support packages and becoming purchasers of the services they need. This will need to be done in accordance with agreed policy and funding guidelines, which consumers and carers should be central to developing.

Specialist mental health non government service providers in the disability and community service sectors should also be involved to ensure greater engagement with what this scheme may mean to current approaches to service delivery and changed expectations regarding consumer interaction with services.

A significant financial, resource and people investment needs to be made to ensure that this scheme is set up as well as it can be from the start. As the issues paper notes, there are advantages and disadvantages for a narrow vs wide scheme.<sup>8</sup> The NMHCCF and the MHCA consider the scheme should be designed to meet the needs of people with a severe disability and their carers and should not be limited to people with a disability from a certain date of commencement of the scheme, but rather is available for those people who need it most right now and in future.

Trying out a narrow scheme as a 'pilot', with possible plans to broaden it, means that wider coverage will be unlikely in an environment of competing demands for taxpayer and other funds. Lessons must be learned from examples which are prolific in the mental health and community sectors: there are a number of important innovative and successful pilot programs that have been undertaken over many years and have not been re-funded or, if they do get further funding, are funded at the initial rate and do not allow for identified enhancements. We would be extremely reluctant to see this scheme derailed by insufficient funds to match community expectations or need.

It makes sense that at least some of the revenue for this scheme is taxation based, much like contributions to Medicare. However, communicating the benefits to the community and why this is a good investment, how it might benefit them/ their family at times, and so forth, is key to ensuring community support for any additional tax required and/or funds diverted from elsewhere. Diversion of funds would, of course, impact further on disability services that are already struggling to meet the needs of consumers and their carers.

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<sup>8</sup> Productivity Commission (2010), op cit, p 20.

The development of this scheme provides an ideal opportunity to better report disability-related outcomes, for example measuring consumer and carer experience at baseline, after a year or two of implementing the scheme, and no more than five yearly after that to see where/how/if the scheme is actually improving the lives of people with disabilities and their carers, as well as areas to improve or enhance.

The overarching entity to implement and deliver this scheme should be set up with a change management culture focussed on consumer and carer identified priorities and capable of growing and changing to meet the needs of its clients by integrating mechanisms like continuous quality improvement approaches into its structure. It is important this is integrated into day to day work schedules and is not just a 'tick box' exercise. This integration would need to be supported by structures in organisational functioning and commitment from senior management for challenges to be addressed. Such an approach would be underpinned by principles such as the Convention on the Rights of Persons with Disabilities, National Standards for Disability Services and the National Standards for Mental Health Services.

The organisation would need to have particular understanding of the principles of recovery in mental health from the beginning to address the needs of people with psychosocial disability. This would ensure a scheme and overarching entity that can grow to meet the needs of all disability consumers and their carers.

We understand the overarching entity will need rigid legislative controls to set it up and define eligibility etc, however front desk staff need to be open to delivering the scheme in the context of the real life experiences of consumers with disability and their carers. For example, although Centrelink has a customer charter that outlines how people accessing Centrelink services can expect to be treated, mental health consumers regularly report their interaction with Centrelink to be difficult, confusing and/or disempowering.<sup>9</sup> The nature of psychosocial disability (and indeed a range of disabilities) is such that it can result in a lack of self confidence, making communication with others challenging, overwhelming or intolerable. For someone with severe and disabling mental illness, this sort of interaction may be almost impossible without sensitive and appropriate staff interaction.

One possible method of greater support to consumers with particular disabilities would be to identify disability-specific units within the overarching entity so, for example, staff working with people with psychosocial disability have expertise, or reference to expertise, in working with people with persistent mental illness. This will allow development of relevant policies and procedures within the overarching entity and for appropriate linkages to be built with relevant peak bodies and other service delivery bodies.

It makes sense to use a model in place already, such as making the overarching entity a Medicare-type entity, as long as the opportunity is used to take what works from Medicare and improve it, for example, by governance arrangements that include consumers and carers with disabilities as part of decision making. The most important part of setting up and designing this important scheme is to ensure

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<sup>9</sup> Mental Health Council of Australia *MHCA submission to the Commonwealth Ombudsman's Own Motion Investigation: Engagement of customers with a mental illness with the social security system October 2009*, available at <http://www.mhca.org.au/submissions>.

consumers and their carers are involved in all aspects of governance, give input to design of eligibility criteria and assessment tools, and provide input to evaluation and improvements for the scheme.

### **Eligibility criteria**

Eligibility assessments need to be relevant to the disability in question and include assessment items that consumers within that disability group consider are reasonable measures for levels of disability. For example, people who have a hearing-related disability and use an aid are assessed differently to people with a sight-related disability and use an aid, but the individuals concerned are likely impacted upon regardless of which disability they have.

Further, these assessments need to also consider the needs of carers. Carers of people with psychosocial disability have advised that they often find that carer payment and carer allowance are difficult to access. A frequent comment in the mental health carer workshops MHCA held nationally in 2008 and 2009, was that application forms are inappropriate for carers of people with mental illness or psychosocial disability, as they do not reflect the type of care required, focusing much more on physical disability. Carers reported that completing the forms requires much effort, particularly if their application has already been rejected.<sup>10</sup>

The MHCA and the NMHCCF support eligibility for access to this scheme for disability acquired through a 'health condition' (not just through accident or misadventure), however want to be clear that this also refers to a mental health condition, as physical disability is often what people think of as a 'disability'. For example, a workplace may consider it meets the needs of people with disabilities by having wheelchair ramps or telecommunications devices for people with hearing impairment, but it may not have policies and procedures in place to deal with an episodic condition such as persistent mental illness.

While we understand that the TOR for this Inquiry, and likely the scheme itself, are not aimed at disabilities related to ageing, it is not clear how linkages will be made between the findings of this Inquiry and the Productivity Commission Inquiry into Aged Care.

If this scheme only covers disability **not** related to ageing, its only hope of successfully meeting the needs of people with disability and their carers as they age is if appropriate parallel attention is given to the aged care disability sector. This is plagued with insufficient services now and will become more urgent with Australia's ageing population. The MHCA submission to the Inquiry into Aged Care outlined our concern that the health of older Australians is already being compromised by the significant challenges they face in accessing appropriate mental health care and for ageing carers in caring for people with psychosocial disabilities.<sup>11</sup>

The impact of long term or severe disability does not disappear when a person turns 65. In fact, as they age a person's care needs may be further increased due

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<sup>10</sup> Mental Health Council of Australia (2009) *Adversity to Advocacy: the lives and hopes of mental health carers*, MHCA: Canberra.

<sup>11</sup> Mental Health Council of Australia *Submission to: The Productivity Commission Inquiry into Aged Care July 2010*, available at <http://www.mhca.org.au/submissions>.

precisely to age-related illness and possibly disability. In 2009, MHCA released *Adversity to Advocacy: the lives and hopes of mental health carers*, a report of survey findings that found it is not uncommon for carers in their 70s to be providing day to day living support in their own home or in the home of their adult children with psychosocial disabilities, who have complex needs and require on call care that is not otherwise available.<sup>12</sup>

Many mental health carers do not know when they will need to be available, which impacts on their ability to work and maintain other life pursuits. Carers of older people are likely (but not always) to be their adult children who may be in their own peak employment years and also raising children. This impacts on their family's ability to earn income, stretches family members to fit more in, and may mean older people with disabilities are institutionalised. A carer who is a spouse may be facing their own age-related illnesses and also have decreased capacity to care for someone with a disability.

Better disability support for older people as well may mean more workers are engaged in employment and paying tax dollars rather than taking unpaid carer roles and may, in turn, support more disability services. Relevant support and assistance may also mean older people with psychosocial disabilities are able to remain in or return to employment.

Means testing eligibility is fraught with problems, as outlined in the issues paper. Basing access to the scheme on assets or income negates the impact disability has on anyone experiencing it and implies disability is somehow 'better' or more easily adapted to if finances are reasonable. Notwithstanding the difficulties for people on lower incomes, where would the line be drawn? Would it adjust based on severity or predicted length of disability? A more just system that meets the principles of the UN Convention would be that it is based primarily on need, regardless of the assets a person has or whether they are employed or access the Disability Support Pension (DSP). It is also the general pattern that families are impacted on by supporting a person with a long term disability, either through direct loss of income or through a carer's ability to work being impacted upon.

Level of need is an appropriate basis for eligibility, but this should not be seen purely as financial need. Obviously people and families on lower incomes have less ability to absorb costs associated with illness and disability. However, many 'working poor' families would struggle, if for example, the ability for one or more family members to work is impacted because they have a disability or are engaged in a caring role. Assessing income alone would not pick up the level of need this family might have.

SANE Australia identified that people with mental illness are often forced to choose between paying for health care (and presumably disability-related) costs or meeting daily needs.<sup>13</sup> Many people with psychosocial disability who meet the Medicare Safety Net one year find that they have all the out of pocket medicines expenses in the first part of the next year until they again meet safety net requirements again. Some recognition of people who meet the safety net year after year could spread out

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<sup>12</sup> Mental Health Council of Australia, 2009, op cit.

<sup>13</sup> SANE Australia (2009), *Research Bulletin 9: Stigma and Mental Illness*, SANE: Melbourne.

some of the costs associated with essential medicines use. Any disability safety net scheme, although likely not part of this insurance scheme, should be set up similarly, with automatic enrolment of anyone accessing disability services.

### **Assessment processes**

Assessment tools and processes need to be designed in collaboration with people with that disability and their carers, to ensure that the impact on their lives is recognised. Health and rehabilitation professionals experienced in working with people with disability, and who will likely be involved in assessment, should also have input to assessment tool design.

There must be specific psychosocial disability-related assessment tools that are applicable to psychological, mental, social, and cognitive functioning as well as physical ability to care for self. Most current assessment tools miss psychosocial disability and are not aimed at anyone who may have periods of wellness, even after long periods of severely disabling illness.

The issues paper refers a lot to aids, tools and appliances, which is common in disability-related discourse. However, people with psychosocial disability probably do not need these and their service-level style and needs will be different to someone with a physical disability. Mental health carers have commented on the level of need when the person they care for is severely ill, and the requirement for carers to assist with communication, dressing, nutrition, and keeping the person safe can be high at these times.<sup>14</sup>

The majority of people with psychosocial disability have other concurrent health conditions that may be severe or disabling.<sup>15</sup> Research suggests that access to medical screening and physical health monitoring is considerably less than for the general population. Life expectancy of people with psychosocial disabilities is up to 25 years less than that of their peers.<sup>16</sup> The scheme must take a holistic approach to 'support' and assist with access to health and other services; there must be no 'wrong door' for a person with disability attempting to access support regardless of which sector or service they first approach.

The mental wellbeing of many people with a disability can be affected by disability, lack of diverse social interaction, frustration, interventions, and other factors. This added layer of emotional distress may be more difficult to live with than the disability. It is often difficult for people with disabilities to seek appropriate support, help or treatment for this distress as matters of privacy, discreet access to help, or even access to premises where help might be available, can thwart efforts to alleviate these issues. Inevitably, this leaves people living with a combined disability and is an example of why the scheme needs to be well linked to health and other disability services, to ensure the most appropriate support is being provided when, where and how it is needed.

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<sup>14</sup> Mental Health Council of Australia (2009), op cit.

<sup>15</sup> Lawrence D, Holman D & Jablensky A (2001) *Duty to Care. Preventable physical illness in people with mental illness*, University of Western Australia: Perth.

<sup>16</sup> Mauer B (2006) *Morbidity and mortality in people with serious mental illness*, Nat. Assn. of State Mental Health Program Directors: USA.

The issues paper discusses daily core activity limitation<sup>17</sup> but we do not see recognition of episodic illness in this discourse. This needs to be explicit. Determination of what is 'severe or profound' disability must include consumer and carer definitions.

Other factors that may need to be acknowledged when assessing need could include recognition that in rural and regional areas an appropriate range of services may not be available or be a long way away, respite services may be less available, and people may not be close to family or friend support. Need could be higher because of all of these or other reasons. However, it should not be assumed that all urbanites are doing well. Consumers' and carers' needs (for example, for respite) should be factored in to needs assessment and recognition that not every person with a disability wants or has 'someone' to care for them who is both willing and able.

Although we refer frequently to people living with psychosocial disabilities and their carers/ family members in this paper, it is a sad reality that for a substantial proportion of people with psychosocial disability there is no remaining carer or family support. The nature of progress from mental illness to disability frequently is accompanied by multiple crises, trauma and social exclusion. This creates distress and isolation from traditional supports and many people end up in social housing or homeless. This means their disability needs are unrecognised and leaves the individual unsupported. Addressing the needs of *all* people with disabilities will require an understanding of the inherent value of every person with a disability and their right to live with whatever supports assist them to live with security and dignity.

Assessment tools must be culturally appropriate, both for Indigenous people and for people from other backgrounds. An example of why this scheme cannot be seen in isolation from health, other disability, and social and welfare initiatives, is where someone is assessed as meeting the eligibility requirements for this scheme, but lives in an area of such general social disadvantage they will not be able to access many or any services to assist them (eg some Indigenous communities, homeless people).

The scheme needs to invest in training and the time required for support, rehabilitation and health professionals both to refer people and (likely) assess people's eligibility. It makes sense that someone closely involved in the ongoing mental health care of a person with psychosocial disability is involved in their assessment, not that the person is referred to a new provider purely for the purposes of assessment. It is frustrating for consumers, carers and their regular health or rehabilitation professionals when assessment is made by an independent 'expert', who might see a consumer when they have a period of wellness.

There are two methods to fund assessments being undertaken by members of the health care or rehabilitation team. One is through the consumer purchase of service model (see *Design elements of the new scheme*) and another a Medicare item number or disability scheme item number for involvement of health professionals. If the latter option is taken, this should be for the full range of mental health and other health professionals likely to be involved in a person's care. For example, a

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<sup>17</sup> Productivity Commission (2010), op cit, p 17.



specialist employment provider or an OT involved in an employment-related return to work arrangement for a person with psychosocial disability may have different assessment of the impact of a person's disability than a GP who sees them for 30 minutes once a month. Each will have insights that are valuable to include in an assessment. Consumer self reporting and carer input to assessment should be part of a holistic approach to best outcomes within a social framework, rather than a medically focussed approach.

### **Additional support and assistance**

It is probably reasonable that the scheme is intended for people with *significant* need of support, however in mental health service systems there are currently insufficient and inadequate services to support people with milder or moderate mental illness. There has been a gradual lessening of available community-based rehabilitation and recovery support and it is often only when illness is severe and impacting on every aspect of someone's life that assistance becomes available. We acknowledge the Productivity Commission is trying to outline a model to make best use of resources to hand, but none of this can be seen in isolation of what other services provide before illness becomes severe and disabling, with longer and harder recovery times (if at all).

The issues paper reference to depression and anxiety as an example of a temporary disability unlikely to require long term care is an example of how mental illness is often mis-perceived.<sup>18</sup> One episode of depression or anxiety may well be 'short term' and also may not even be severe, *provided* there is appropriate treatment and support available. However, there are, unfortunately, many people with mental illnesses, including depression and anxiety, who do not access treatment, who do have periods of severe and disabling illness, who do experience this for extended periods, and who do rely on support from carers, family and friends. We would not want to see these vulnerable people miss out on access to support through this scheme, merely because depression and anxiety are often seen as transient or less serious.

### **Individual decision making**

People with a disability should be able to make decisions about the package of care they wish to receive. Providing a consumer with the ability to make this decision, either through a direct monetary amount for a package of care, or through financing their preferred options, would provide them with choice of what services they most need, who the service provider would be and when and where the service could be provided.

It is likely that many consumers or their carers would want to be responsible for organising service provision themselves, but alternatively, they could purchase the services of a 'case manager' (or other) to organise this. However, it would be up to service organisations to offer a wider variety of quality services that would actually meet the needs of the consumer, and consumers could choose a service provider who meets their needs in an open market context. Consumers in rural and remote areas are not likely to be lucky enough to choose which services they receive, as

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<sup>18</sup> Productivity Commission (2010), op cit, p 7.

there are already insufficient services in these areas. An incentive for enhanced service provision in these areas could be considered. Funding arrangements should be portable, so that consumers can change their service providers easily and enable people to move house, move interstate etc and still retain the assessed level of care.

Special provisions will need to be made to support individual decision making by the most vulnerable people with disabilities, such as people who are homeless or lack stable accommodation, or are living in socially disadvantaged communities. Supporting some form of advance decision-making, long before people are 'falling through the cracks' may be one way to ensure appropriate support and care is provided for longer, or keeps people in touch with some form of service.

### **Improvements to disability services**

Better linkages between health and disability services is key to ensure success of this scheme and that it makes a real difference to people with disabilities and their carers. People with disabilities will be using both sectors and it needs to be seamless. For example, out of pocket costs should be counted in one safety net. Consumers should not have to meet the Medicare Safety Net, a disability care safety net (if there is one), and a threshold for claiming tax benefits for out of pocket health expenses. There needs to be recognition that having any long term health condition, particularly one that is disabling, costs a lot for that person and their support networks. Linkages should also be strengthened across other social and welfare areas, such as better housing, employment support, aged care, etc.

### **Early intervention**

The issues paper lists a number of things that may be 'enough' for people with milder disability.<sup>19</sup> For example, 'acting on discriminatory social attitudes' may well be enough to encourage more people with 'less restrictive disabilities' to participate more fully in their community, however, this is not being met now. If it is ignored with the introduction of this scheme (and we do understand the scheme is not intended to be the only method to deal with disability-related need), when will it be done? Who and how? Implementing something as groundbreaking as this scheme gives us an opportunity to look at how Australia addresses disability and use it as a platform to do more to challenge stigma and discriminatory attitudes and behaviours, enhance opportunities for people with disabilities, and implement effective strategies to keep more people with 'milder' disabilities from becoming those in most need. This will, of course, require resources and that should not detract from this important scheme, but it is worthy of implementing in conjunction with this scheme.

### **Community participation by people with disability and their carers**

People with a disability bear financial costs of living with a disability and may have limited opportunity to plan for future needs when so much is hand to mouth on a daily basis. In 2007, the MHCA released *Let's Get to Work: A National Mental Health Employment Strategy for Australia*<sup>20</sup> that highlighted a person with a mental illness must be at the centre of decision making about their lives, including decisions about employment participation and remaining or returning to work. If the process of

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<sup>19</sup> Productivity Commission (2010), op cit, p 16.

<sup>20</sup> Mental Health Council of Australia (2007) *Let's Get to Work: A National Mental Health Employment Strategy for Australia*, MHCA.

seeking or remaining in employment or participating in training or vocational support is disempowering for the individual then it is unlikely to be successful.

There are high levels of unemployment and non-participation in the workforce for mental health consumers in Australia.<sup>21</sup> People with psychosocial disability who access the DSP may well move to full or partial employment during periods of wellness. This can be after very disabling periods of illness and it should not be assumed that once on DSP, always on DSP.

There are currently not enough opportunities for people with psychosocial disability to work. New opportunities need to be made for specialised employment programs to create structured employment initiatives and guidelines for government related disability employment programs to deal more effectively with the long term employment needs of people with disabilities. For example, the Disability Maintenance Instrument (DMI) remains a difficult and inefficient tool to measure the level or type of psychosocial support required in a disability employment program.

There is also not enough information and support to keep people with less persistent mental illness in employment as one method to support participation in their community and perhaps prevent spiralling into a more severe illness state. Workplaces generally do not have enough flexibility around support or caring responsibilities, particularly for an episodic illness when need for support or care may change with little notice.

Carers also find that the demands of their role directly reduces their capacity to participate in paid employment, with most primary carers working only part time.<sup>22</sup> The poor rates of wellbeing for carers is outlined in the Productivity Commission's issues paper. There is an enormous impact on the whole family worrying about what will happen when a primary carer is no longer around or simply no longer able to care.

One model to consider for greater community participation by people with a disability related to episodic illness is one where an assessed level of need is made and people with a disability and their carers know that they are entitled to and can access care to that level of need when it is needed, without waiting for a new assessment with each period of severe illness. They may be more likely then to commit to activities such as involvement in the community and employment and access the actual amount of support they need at any one time, rather than an 'all in or all out' access model.

### **Workforce options**

There is huge scope in the disability sector to develop positions and career pathways in the area of the 'peer workforce' or consumer or carer identified workforce. This workforce is essential in supporting recovery focussed services for mental health consumers and carers and the Australian evidence on the effectiveness and cost

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<sup>21</sup> Ibid, p 17.

<sup>22</sup> House of Representatives Standing Committee on Family, Housing, Community and Youth (2009) *Who Cares: report into the inquiry into better support for carers*, Parliament of the Commonwealth of Australia.

savings provided in mental health service provision is clear.<sup>23</sup> These roles also provide employment opportunities and pathways to employment outside the mental health sector for mental health consumers and carers.

The NMHCCF is currently finalising its Position Statement on the mental health consumer and carer workforce and how it can best be supported through the development of a national competency framework and training.<sup>24</sup> The Position Statement describes the range of opportunities and barriers for the development of this workforce and answers many of the questions outlined in the issues paper regarding workforce.<sup>25</sup>

There are models for employing peer workers, for example through the Personal Helpers and Mentors Program (PHAMS). Under this program, mental health consumers are employed as consumer peer workers to provide assistance to the most marginalised of people with mental illness who are missed by regular community supports. In the mental health sector there is such great need for community support that even those people who regularly have contact with mental health services and community agencies (not necessarily in the target group for PHAMS services) also often need this support.

The NMHCCF and MHCA have previously called for the development of specialised peer support roles in the criminal justice sector<sup>26</sup> and in Centrelink<sup>27</sup> to improve the provision of services for mental health consumers and carers. These roles would provide assistance to consumers and carers accessing these services in ways that are urgently needed but currently not provided.

### **Financing the scheme**

Financing the introduction of this scheme must adequately fund current needs, and also look ahead to funding requirements needed in future. Of course, the MHCA and the NMHCCF recognise that a greater investment in early intervention care and support means future needs might well be reduced.

As outlined above, it is probably reasonable to find at least some of the funds for this scheme through a taxation levy, like the Medicare levy. However, we would only support this if there was a quarantined amount, for example x% of GDP, to ensure that government/ political prioritising does not impinge on the future amount available for this scheme. Implementation of the scheme may also benefit from cost savings

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<sup>23</sup> Lawn S, Smith A, Hunter K (2008) *Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service*, Journal of Mental Health, October 2008, 17(5).

<sup>24</sup> National Mental Health Consumer and Carer Forum (2010) *Supporting and developing the consumer and carer identified workforce – a strategic approach to recovery*, available at <http://www.nmhccf.org.au/workforce>.

<sup>25</sup> Productivity Commission (2010), op cit, p 39.

<sup>26</sup> National Mental Health Consumer and Carer Forum (2010) *NMHCCF comment on the consultation draft Diversion and support of offenders with a mental illness, guidelines for best practice 2010*, available at <http://www.nmhccf.org.au/submissions>.

<sup>27</sup> Mental Health Council of Australia (2009) *MHCA submission to the Commonwealth Ombudsman's Own Motion Investigation: Engagement of customers with a mental illness with the social security system October 2009* available at . <http://www.mhca.org.au/submissions>.

through better education about avoiding accidents and using early interventions, as the TAC example in the issues paper highlights.<sup>28</sup>

‘Needs inflation’ referred to in the issues paper<sup>29</sup> is likely only because existing arrangements that would support the scheme are so inadequate. It is naive to isolate the new scheme and be clear what it will and will not cover when people with disability are already being so inadequately serviced. Further, it is unjust to apply this scheme only to new cases of disability after the date of commencement. While this may be cost effective, it does little to address the needs of people with disability now who have been underserved for years.

Waiting lists should not be used as a way of managing costs for the scheme<sup>30</sup> as waiting time impacts on services people need that may, as an early intervention, save costs in the long run. Obviously we support a sustainable scheme or it is little use to anyone, but how this is done will need to be carefully managed. A ‘reasonableness’ test, as outlined in the issues paper,<sup>31</sup> may be one method to allow for local adjustment of eligibility criteria based on service availability.

As outlined above (see *Individual decision making*), the NMHCCF and the MHCA support the person with a disability (and their carers) developing their own support package. Appropriate policies and guidelines in place around how this would work in practice would address the concerns outlined in the issues paper. For example, while individuals could make decisions about what care they would purchase with their allocation, actual payment for this and oversight could remain with the central body.

Some recognition must be included of carer need. What if carers want some of the allocated funds spent on respite but the person with a disability does not? Who will determine this is a reasonable decision? Peer-run decision making oversight mechanisms may be one method of addressing the needs of both consumers and their carers.

Mental health carers often are impacted on financially by their caring role.<sup>32</sup> Carers often pay for the basic needs of the person that they care for, including medication, other medical costs and transport. The issues paper outlines concern about payment for caring, however we consider it unlikely great numbers of carers will use this scheme as an opportunity to make a dollar or two for themselves. This small risk needs to be balanced with the fact that mental health carers do miss out on income because they are in a caring role.

Strict guidelines around when someone can make a decision to access individualised fund allocations and encouraging preparation for periods of severe illness, such as formal advance decision-making, combined with peer review mechanisms may result in the best service outcomes for consumers as well as acknowledging carers’ needs.

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<sup>28</sup> Productivity Commission (2010), op cit, p 36.

<sup>29</sup> Productivity Commission (2010), op cit, p 20.

<sup>30</sup> Productivity Commission (2010), op cit, p 34.

<sup>31</sup> Productivity Commission (2010), op cit, p 34.

<sup>32</sup> Mental Health Council of Australia (2009), op cit.

## **Conclusion**

The MHCA and the NMHCCF strongly support the implementation of this scheme and acknowledge the important work of the Productivity Commission in outlining the concerns and canvassing input to develop a rational, viable and sustainable scheme.

Psychosocial disability needs to be an integral part of disability-related discourse and its visibility enhanced. People with psychosocial disability and their carers need to be part of governance and accountability arrangements for the overarching entity. If the scheme is designed with consumer and carer input at the forefront, it will have the highest likelihood of meeting the needs of those who need it most.

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